

Theory of Infants' Transition Management from the Neonatal Intensive Care Unit to Home: a Qualitative Study

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Abstract

Background: Infant's transition is a challenge for parents and the health system that requires ongoing assessment and management to improve each newborn's growth and development. The purpose of this study was to explore the management of infant's transition from neonatal intensive care unit (NICU) to home.

Materials and Methods: We used a grounded theory study to explore and describe the management of infants' transition from the NICU to the home. Interviews were conducted with 31 professionals and 20 family members, and participant observations were made in hospitals, clinics, and one physician office. MAXQDA was utilized for coding and categorizing data.

Results: The theory illustrated six phenomena: An unexpected separation; A crisis situation; Mother-infant rebonding; Protection of the infant's health; Promotion of growth and development; and Inadequate management causing disability. Together, these formed a three-phase process consisting of: A threat to the infant's life, Efforts to save the infant's life, and Continuation of life.

Conclusion: Development of the theory of infants transition provides a three phases process (A threat to the infant's life, Efforts to save the infant's life, and Continuation of life), that can yield guidelines to manage the infant's transition in prevent mother-infant separation, support parents in their role as primary caregivers, and follow up with individual home visits by nurses.

Key Words: Discharge, Grounded Theory, NICU, Newborn, Qualitative study, Transition.

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1- INTRODUCTION

Hospitalization in neonatal intensive care unit (NICU) is a challenge for the infant, the family, and the health system, because many infants require a long stay due to their need for intensive care (1). Premature infants can experience several medical problems during the first year of life, as well as high rates of hospitalization (2). A study in the U.S.A showed that 15% of preterm infants required at least one re-hospitalization within the first year of life³. In a 3 months follow up study in Iran, in which a 1,500g weight was a criterion for discharge, 15% of included infants were re-hospitalized during the follow up period (4). In a 3 years follow up study in Iran, 7% of 988 infants had been readmitted to the NICU (5). Therefore, re-hospitalization is a problem for premature infant.

On the other hand, common emotional reactions among parents of infants in an NICU are stress, anxiety, depression, and grief (6). The "infant's appearance and behavior and special treatment", "the mother–infant relationship", and "environmental factors" emerged as stressors in another, Iranian study. The majority of the mothers in that study described separation from the infants as the main stressor. Feelings of hopelessness also influenced their interaction with the infants (7).

Mother's role in caring the infant in NICU has changed over time and is still changing. Attachment as a unique relationship between the mother and infant has been reported to commence before birth. Hospitalization disrupts this relationship. Kangaroo Mother Care (KMC) is a care model that facilitates the mother–infant attachment as soon as possible after birth and also facilitates the neonate's transition from intra- to extra-uterine life (8). In a study in the Iranian NICU revealed KMC applied less than one hour because of some barriers.

Family-centered care (FCC) has been developed to support mothers' and fathers' roles since the care professionals have recognized the importance of early mother–infant interaction on mother–infant bonding and attachment as well as infant's social and cognitive development (9). It has been suggested that partnership between the NICU staff and parents should begin at the infant entrance to the NICU, and should even continue after discharge. The focus on discharge planning is facilitation of a safe transition to the home. Commonly stated aims of discharge planning are to improve parents' confidence in taking over the care of their child, decrease the risk of infection transmission and re-hospitalization, and support normal growth and development (10-11).

Regarding to re-hospitalization, parents' anxiety and stress, altered attachment and necessitation of parents' participation in the NICU, it needs to have a holistic view to this process. In fact, infants' transition from the NICU to home is a complex process that infants and their families encounter with many challenges. To overcome the challenges, researchers considered a qualitative research with grounded theory approach in this process to obtain comprehensive and rich descriptions about all efforts, for mothers and infants, made by both professionals and family members either in hospital and after the infants' discharge, and about the context in which this discharge occurs. Grounded theory enables the researcher to seek out and conceptualise the latent social patterns and structures through the process of infant passage from NICU to home (12). This study was to explore interactions, experiences, interventions, and everything related to infants' transition. The identification of new aspects of this phenomenon can enrich health professionals' body of knowledge and improve the management of the

transition process. Thus, the aim of this study was to develop the present grounded theory about the management of infants' transition from the NICU to home.

2- MATERIALS AND METHODS

2-1. Method

Grounded theory approach was used for discovering the basic social processes that explain how professionals, parents, and family members can resolve the challenge of achieving a functional transition. The grounded theory interprets social interactions in the settings and explains interrelationship between the perception meaning of the participant and their action through the meaning of symbols. Grounded theory translates and discovers new understandings of human beings' behaviors that are generated from the meaning of symbols and gain knowledge about the socially shared meaning that forms the behaviors and the reality of the participants (12). There are studies that use this approach to discover some process in nurse–mother interaction in the care of children, mothers' parenting experiences when their preterm infants were in NICUs, and emotions of pregnant Iranian Kurdish women influenced their choice of the mode of child delivery (13-15). This method was appropriate for this study because the study explains a process of social interactions and experiences through families and health professionals in the NICU and after discharging from hospital.

2-2. Research setting

The research was conducted in six NICUs at university hospitals in three big cities (Tabriz-Isfahan and Tehran) of Iran from June 2012 to September 2014. The NICUs were divided into three levels including: level 3, for neonates in a serious condition or under ventilation and needing special care; level 2, for neonates who require a certain degree of monitoring and nursing care; and level 1, for premature or term

neonates with mild problems such as poor feeding skills or hyperbilirubinemia. During the study period, the NICUs admitted neonates from 26 weeks' gestational age (GA) as well as newborn, full term infants up to 28 days after birth, with weights ranging between 600 grams and 4,500 grams.

2-3. Participants and data collection

Purposive sampling technique with the aim of obtaining rich information was used to select 51 nurses, physicians, parents, and grandmothers for participation. The participants were identified by the head nurses, after which they were provided with oral and written information about, and recruited to, the study by the first author (M.N.) (**Table.1**). Data collection was performed by the first author (M.N.) who has practically experienced in the neonatal unit for 19 years and was trained for the qualitative study in the PhD course. She used in-depth and semi-structured interviews that lasted from 20 minutes to 3 hours. The interviews commenced with a few opening questions. The main questions, posed to nurses and physicians were "What are your experiences of discharging infants from the NICU and which criteria are applied to their readiness for discharge?" and "How do you follow up infants after discharge?"

In addition, the researcher was present in an NICU for 200 hours to conduct participant observations as a staff member in order to explore the social practices, performed by the participants. The process and content of the observations were systematically documented in her field notes. These included the interactions between the researcher and parents, nurses, and physicians, as well as observation of non-verbal and verbal behavior among personnel, mother, and infant, and all interventions, applied for preparing the infant's discharge from the NICU. Patients' medical charts were

reviewed to assess and confirm the data such as demographic information, prescriptions of medications and treatment, and the infants' medical status. In order to follow up the infants after discharge, physicians and family members were interviewed in neonatal clinics and in the office of one of the physicians. To follow up the process, a semi-structured, face -to-face or telephone interview was used throughout the process with three mothers once a month and two mothers every 2 months, from 2 months after discharge for 12 subsequent months.

2-4. Ethical considerations

The ethics committees of the universities of medical sciences approved the data collection process of the study. Being assured of anonymity, the participants had the right to terminate the study any time before or during the interview without having to give any explanation. The parents were ensured that their termination would not affect their infants' care in any way.

2-5. Data analysis

The interviews were transcribed verbatim and coded. The qualitative data analysis package MAXQDA was used for coding the initial stages. Three stages of data analysis that are involved in grounded theory are open coding, axial coding, and selective coding. In the open coding stage, each transcript is read and coded line by line. Then, similar codes are grouped into subcategories followed by grouping similar categories into main categories. In the axial coding stage, the data are connected by use of a "coding paradigm", a system of coding that seeks to identify causal relationships between categories (12). In the third stage, selective coding, the core category (core variable) is selected and systematically related to other categories. Credibility was established through researcher's prolonged involvement and presence in the NICUs of

the study. Member checking with mothers, nurses, and physicians was also used to ensure the accuracy throughout the process. In addition, some well- informed experts reviewed and approved the transcripts in relation to the analysis. Triangulation, using both interviews and participant observation for data collection, was applied for achieving dependability.

3- RESULTS

The data analysis emerged six main phenomena that are further categorized in a three-phase process of "A threat to the infant's life", "Efforts to save the infant's life", and "Continuation of life". Each of these phases comprises two phenomena (**Figure.1**).

3-1. Threat to the infant's life

3-1-1. Un-expected separation

Contexts and conditions that interrupt mother - infant relationship are the mother's own medical, psychological, and social difficulties and inadequate support. Could the health system support the mother adequately, premature birth would be prevented, leading to a normal delivery. A neonatologist explained: "We have a lot of Cesarean sections because, in comparison with normal delivery, more money is made in this way; consequently, we face more prematurity, asphyxia, and so on". Adverse conditions such as domestic violation and difficult life events can also cause preterm delivery. This is illustrated by the following quotation from a mother: "It was the early days of our marriage. I had serious problems with my mother-in-law, my husband beat me and my water sac (amniotic membrane) ruptured". During pregnancy, the needs of fetus are met by placenta, but these must be met artificially after the birth. The strategy is to shift the infant's dependency from mother to technological equipment such as respirator for assisted ventilation or treatment with continuous positive

airway pressure (CPAP), and medical and nursing care. One nurse said: "The infants, weighing about 600 grams, will die by the time of delivery, if they are not put under ventilation, they experience a separation period". This separation causes increased infant stress as the infant has to adjust to the extra uterine environment. The delivery, emergency procedures after birth, and admission to the NICU involve invasive procedures. A nurse explained: "At the time of birth, we push a tube into the infant's mouth (to suction the mucus), immediately insert a nasogastric tube (NGT), inject vitamin K at one thigh and hepatitis vaccine at the other ..., when do we let the neonate have skin-to-skin contact"?! The conditions in this phase can be summarized as unexpected mother–infant separation and substituting technological and professional care for mother care, resulting in increased infant stress.

3-1-2. Crisis situation

The infant's life is threatened by an unexpected separation from the mother due to a premature birth and/or neonatal illness, which may cause the infant crisis such as respiratory distress and consequently the need for intensive care. One nurse said: "Most patients have respiratory problems. They have to be under ventilation, and they need administration of surfactant". Infants' respiratory problems constitute the most important challenge in the NICU. A neonatologist explained: "Respiratory management is the most important step. We administer surfactant and start CPAP treatment in the delivery room for preterm infants".

3-2. Efforts to save the infant's life

3-2-1. Mother–infant rebonding

Rebonding, the process in which the mother retains the normal status of bonding to the infant, depends partly on how deep the infant attains physiological

stability and partly on the degree of mother's readiness to assume that relationship. Usually, mothers of premature infants are not ready to take care of their children immediately after the delivery. One grandmother stated: "In the first 2 days, my daughter was not physically well; it took 3 days before she could go and see her baby. How could she take care of her baby?"

A mother explained: "I couldn't come here, I have to take care of three children at home and the hospital is too far from my home". The health system and professionals had taken measures to better prepare mothers to take care of their babies. A unit had been equipped with several beds and a refrigerator to encourage mothers to stay for breastfeeding and Kangaroo Mother Care (KMC). One nurse explained: "Recently, we equipped the unit (NICU) with a sofa for the mothers stay in and we help them to apply KMC". Thus, rebonding occurs once the mother and infant are abundantly stable. The strategy is to support mothers' presence, KMC, and breastfeeding for promoting rebonding.

3-2-2. Protection of the infant's health

Infants need protection to overcome the critical period and attain respiratory stability. To adapt to extra uterine life, they also need to gain weight and spend time outside the incubator, have skin to skin contact with, or held, by their parents. Then, they may be transferred to the intermediate care unit. Some infants need hospital treatment for some type of illnesses. A head nurse explained: "Our infants are not severely ill, but they may have to complete a period of antibiotic therapy, and they need seizure control, or gain weight". Health care providers help the infant attain physiological stability according to certain criteria such as no need of additional oxygen, completed antibiotic therapy, and a lower bilirubin level. They also make efforts to educate

and instruct mothers in breastfeeding and taking care of their babies. One nurse said: "Mothers don't know how to give their babies bath. They are scared and don't know what to do if the baby has apnea".

Preparation for discharge should start at the time of admission. It can be done through both giving oral information and practice, and persisted up to the final discharge from the NICU. A mother who had recently given her baby a birth described the training as follows:

"I am taught how to breastfeed my child at home. I know the signs of a hungry baby. How to check the nasogastric tube, give a bath and clean him".

"Efforts to save the infant's life" was the core variable in this study. To save the infant's life, professionals should perform required activities, with parents' participation, to support mother-infant rebonding and protect infants' health.

3-3. Continuation of life

3-3-1. Promotion of growth and development

An infant's growth and development depend on the situation and conditions. The strategy is to support this in a step by step follow up program. When parents believe their infant's capacity to survive and recover, they will make optimal efforts to support his/her future development. A neonatologist described his experience as follows:

"The positive point is that the families have recognized their infants' capacity to survive and develop. I have a patient who is 4 years old, whose mother is in contact with me".

During field studies and at the clinics, the first author (M.N.) found out that some parents employed private nurses to help them care their baby after discharge. A mother said: "Thanks God, we got a nurse at home. The baby weighed 600 grams at

birth in hospital. She helped my baby gain weight to weigh 1.5 kg within 2 months".

The families were responsible to adhere to follow the program at a medical office or a clinic after discharge. A mother explained: "After hospital, we go to the office of the physician who discharged my baby". The aims of the regular follow up are to check that the infants have a normal growth and development. As one physician stated: "Gaining weight is so important. Therefore, we measure head circumference, height and weight". The mothers are asked to describe developmental skills such as motor activity, head control, sitting; and we inform them about feeding, based on the child's age, and about child care.

3-3-2. In-adequate management causing disability

In some cases, discontinuation of the medical and nursing care and an inadequate follow up system provide a context that can contribute to disability. In the hospital, the infants are under supervision of health professionals. The infant's and the family's contacts with health and medical care providers changes after discharge at home. Depending on the family's cultural context, this lack of continuity can differ from partial to complete. Where there is no, or very little, continuity, this may result in disability and even death of children.

At the discharge, the health care providers advise parents in follow up program, aiming to maintain contact continuity as far as possible. However, as parents are responsible for participation in this program, problems may occur. A nurse described one experience that she had: "We had a baby who was under ventilation for several weeks; all of us took care of him for 2 months and taught his mother. Two days after discharge, he was dead". Infants' discharge to home means that they are exposed to the family's customs and preferences.

Another nurse said: "Culture is so important. We cannot change it easily. Last night, we had a 45 days old infant who had been given herbal medicine. We had to insert an NGT for lavage of gastric contents". Absence of an organized system to follow up the infant is a factor that provides the context for disability. Most participants had experienced lack of compliance in the follow up program. A neonatologist said: "As soon as a mother leaves the hospital, you don't see her again. Her baby is lost in the society. We have no screening system for families and home visits". Poor follow up and unmet growth and developmental needs contribute to infant disability. The participants described infants with

neurodevelopmental sequelae and other types of impairment. One neonatologist explained: "Yesterday, a baby was examined who had visual impairment. He had been under ventilation for 5 weeks".

During the field studies in a rehabilitation clinic, a 15 months old boy who was unable to stand, and a 12 months old girl who could not sit had not participated in any regular follow up after the discharge from the NICU according to their mothers' information. "Continuation of life" was the third phase in the process of infants' transition to home. Although, most infants show normal growth and development, some infants experience a variety of problems or disability during their life.

Table-1: Participants Characteristic

Participants	Number	Age (years) range	Experience in NICU (year)
Nurses (female)	23	25-58	3-18
Clinical nurse	17	25-50	3-15
Head nurse	3	38-58	10-18
Nursing instructor	2	40-48	10-15
Physicians (male)	7	35-45	2-10
Neonatologists	5	37-45	2-10
Fellowship	1	35	2
Ophthalmologists	1	44	8
Families	21	17-60	-
Mothers	17	17-35	-
Fathers	2	22-32	-
Grandmother	2	45-60	-

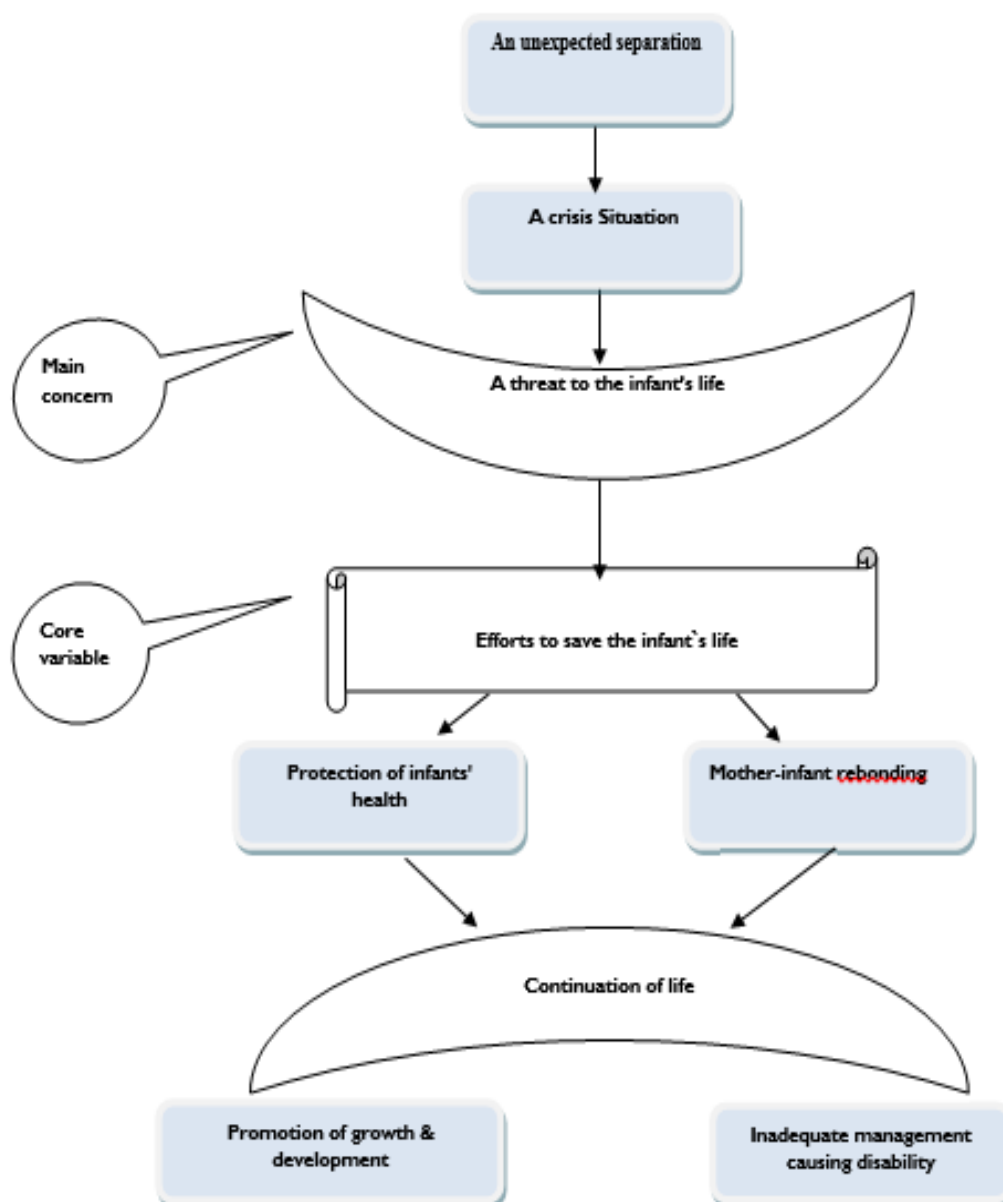


Fig.1: Description of Infants' Transition Management, a three-phase process within six main phenomena

First phase: A threat to the infant's life (1. an unexpected separation 2. a crisis situation). The **second** phase: Efforts to save the infant's life (1. protection of the infant's health 2. mother-infant rebonding). The **third** phases: Continuation of life (1.promotion of growth and development 2. Inadequate management causing disability).

4- DISCUSSION

Based on the three-phase process with its well-integrated set of phenomena, a grounded theory developed for the management of infants' transition from the NICU to home.

4-1. A threat to the infant's life

The results showed that unexpected separation and crisis situation are the two phenomena that threaten the infant's life. Apart from the reason, Cesarean section before term leads to unexpected

separation. According to the reports, released by the medical science universities of Iran, 7.2% of all newborn infants have low birth weight (16). A study in Iranian university hospitals found that the elective Cesarean section rate had doubled during the 5-year period from 1999 to 2003 (17). In another study, conducted in Iranian university and private maternity hospitals, the rates of elective Cesarean section were 47% and 84%, respectively (18). In the U.S.A, nearly one-third of the births in 2008 were by Cesarean section (19). As elective Cesarean delivery is consistently associated with the risk of infant respiratory, morbidity, as well as increased intrapartum and neonatal mortality, compared to vaginal delivery, Cesarean delivery should not be performed before term unless necessary (20).

Mothers' statements illustrate the role of stressful life events and crisis situation during the prenatal period, such as domestic violence, as risk factors for premature delivery. After the delivery, mothers with severely ill infants in the NICU often blame themselves for having given preterm birth and sometimes develop posttraumatic stress syndrome (21-22).

Based on our study participants' descriptions, it can be concluded that inadequate support to mothers, maternal medical/psychosocial problems, and inadequate medical and nursing care render the unexpected separation even more stressful for mothers and infants. This explains why mothers' predominant fear concerned their infants' survival; hence, the phase "A threat to the infant's life". Nurses emphasized the discomfort, pain, and stress experienced by infants because of the intensive care treatment. In summary, the first phase in infants' transition outlines how and why infants enter the NICU and why a threat to the infant's life is the main concern for both professionals and families.

4-2. Efforts to save the infant's life

In the third phase, promotion of growth and development and inadequate management causing disability were outcomes of the management of infants' transition. Having survived the initial crisis and adjusted to extra-uterine life, most infants will achieve normal development, thanks to the efforts of professionals and the family. The combined efforts of mothers and physicians can improve the infants' growth and development, provided that the parents participate in adequate follow up after discharge (31). In Iran, a study found that adequate instruction to parents during discharge planning resulted in higher compliance during follow up (32). Non-attendance in neonatal follow up programs is associated with less use of required services and underreporting of the developmental outcomes of these infants; therefore, strategies should be implemented to address potential barriers to access to, and attendance of, these programs (33).

In inadequate management causing disability phenomenon, infants' risk of dying is increased. In addition, disabled children cause excessive expenditure, both for the health system and the family, because of their need for therapeutic, nursing, and educational interventions. These children may severely interfere with the family's functioning.

4-1. Limitations of the study

There were some limitations in the study. No home visit services were available for infants who are discharge from the NICU. Parents have to visit the physician for follow up care in the office. Nurses were not involved in follow up programs. They work in the hospitals and have no position as a consultant in society. Also, fathers were not free to come to the NICU as they want whether daily or long time because of cultural and religious limitations.

5- CONCLUSION

The three-phase process in this grounded theory study involved infants' health, families, and the health system. We conclude that guidelines for management of infants' transition should address conditions and contexts that cause unexpected separation. Early introduction of skin-to-skin contact, lactation, and breastfeeding counseling, and preparation of mothers and fathers as primary caregivers are essential interventions. Plans for step-by-step follow up, based on each infant's needs, and a home visit program with nurses taking a prominent role can contribute to optimal growth and development.

6- CONFLICT OF INTEREST: None.

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